DOCUMENT RESUME

ED 366 148 EC 302 743

AUTHOR	Brouilette, Ron; Mariga, Lilian
TITLE	Community-Based Approaches for Individuals with Mental Handicap: An African Experience.
INSTITUTION	International League of Societies for Persons with Mental Handicaps, Brussels (Belgium).
REPORT NO	ISBN-2-930078-01-4
PUB DATE	93
NOTE	56p.
AVAILABLE FROM	International League of Societies for Persons with Mental Handicap, 248 Avenue Louise, Box 17, B-1050 Brussels, Belgium.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	Community Programs; *Community Services; Delivery Systems; *Developing Nations; Foreign Countries; Mental Disorders; *Mental Retardation; Normalization (Disabilities); Program Development; Program Evaluation; *Rehabilitation; Resources; *Social Integration
IDENTIFIERS	*Africa; *Community Based Rehabilitation

ABSTRACT

This booklet addresses issues concerning community-based rehabilitation (CBR) services for people with mental handicaps, especially in Africa. The first section explains CBR services, with subsections on overcoming exclusion, a definition, normalization and community participation, family participation, CBR and mental handicap projects in Africa, service user participation, advantages and disadvantages of CBR, structure and activities of CBR, and the relationship between primary health care and CBR. The next section considers ways to include people with mental handicaps in CBR projects. These include: community integration through increasing public acceptance, developing and using individual functional curricula and methods, inclusion in local preschools and schools, and inclusion in local employment and housing. Next, specific strategies for developing CBR services are addressed, among which are a public awareness campaign, establishment of a local committee, networking with local services, personnel training, recreational activities, and development of a volunteer corps. The fourth section considers evaluation of CBR services. It addresses establishing baselines, determining outcome measures, measuring cost effectiveness, and establishing evaluation criteria. A section on resources offers guidance on obtaining help and funding. The last section briefly considers the need for research. Two appendices include a CBR checklist and addresses of resources in CBR. (Contains 51 references.) (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 366 148

Community-based Approaches for Individuals with Mental Handicap

An African experience

by Ron Brouilette and Lilian Mariga

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

1993

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

P. J. Rinour

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

BEST COPY AVAILABLE

International League of Societies for Persons with Mental Handicap

Community-Based Approaches for Individuals with Mental Handicap

An African Experience

by

Ron Brouillette

and

Lilian Mariga

1993

International League of Societies
for Persons with Mental Handicap
248 Avenue Louise
B-1050 Brussels (Belgium)

© 1993 by ILSMH
Dépôt légal D/1993/0990/5
N° ISBN 2-930078-01-4

Outline of booklet

page

Foreword 5

1. What are Community-Based Rehabilitation (CBR) services ?

A. Overcoming exclusion 7

B. Definition (WHO) 9

C. Normalisation, community participation and development 11

D. Family participation (1994) 14

- *CBR and mental handicap projects in Africa: Emerging trends* 16

E. Service user participation 17

F. Advantages and disadvantages of CBR 18

G. Structure and activities of CBR 20

H. The relationship between Primary Health Care and CBR 21

2. How to include services for people with mental handicaps in CBR projects

A. Community integration through public acceptance 22

B. Developing and using individual functional curricula and methods 23

C. Inclusion in local preschools 24

D. Inclusion in local schools 25

E. Inclusion in local employment and housing 26

3. Specific strategies for developing CBR services

A. General guidelines 27
B. Public awareness campaign 29
C. Establishment of a local committee 30
D. Networking with local services 31
E. Personnel training for local service providers 31
F. Preschool/Portage schemes 32
G. Recreational activities (Special Olympics) 34
H. Development of paradigm of early success in vocations 34
I. Development of a volunteer corps 35
- *An African model of exemplary practice* 36

4. Evaluating the quality of CBR services

A. Why evaluate effectiveness and quality? 37
B. How to establish baselines 38
C. How to determine outcome measures 38
D. How to measure cost effectiveness 38
E. How to determine quality assurance in normalisation terms 39
F. Evaluation criteria 39
G. Reporting success 40

5. Resources

A. Where to get more help and possible funding 41
B. Writing funding proposals for CBR projects 42

6. The Need for research 44

Appendix A: Is your project CBR ? 45
Appendix B: Some useful addresses of resources in CBR 47
Bibliography 48

Foreword

by Victor Wahlström, President ILSMH

My experiences in Kenya over the years and more recently with the countries in Network Africa and the new African Federation have made me increasingly aware of the need to seek with concerned citizens of these nations alternatives to the western, institutional mistakes made in educating and caring for children and adults with mental handicaps.

Community-based rehabilitation (CBR) has, over the past decade, gained in popularity as an efficient and effective means to meet the mobility and other more obvious medically related needs of disabled people. This non-formal, grass-roots approach, however, has rarely been applied to improve the lives of people with mental handicaps for whom easy solutions are less likely or not all together desired.

The League, recognising the tremendous short-fall in the availability of needed services, is optimistic about the use of community-based approaches as a way to appropriately empower families and greater numbers of people with mental handicaps to participate more actively and independently in their communities.

As part of its promotion of community-based methods, the League has prompted its MORE committee to expand its activities in Mobilising Resources and infuse the requirements of developing nations throughout the League's work. In addition, the League has established a task force on CBR to serve as a resource group to rethink and promote community based strategies that involve and benefit people with mental handicaps and their families. A task force on the Family has also been established in preparation for the 1994 International Year of the Family.

Many of the important issues presented in this publication were discussed and debated by leaders in the area of CBR during the League's CBR seminar held in Nairobi in September 1992. The conclusions from this seminar are integrated into this publication. This publication has been written by two long-standing MORE committee members, Lilian Mariga and Ron Brouillette, who organised the Nairobi seminar and who share with us their first-hand experiences in community-based approaches.

We hope this booklet will serve to remind its readers of the naturalness and relevance of community-based approaches and the valuable premise of Schumacher that *Small is Still Beautiful*.

Victor Wahlström
President, ILSMH

April 1993

1

What are community-based services ?

A. Overcoming the exclusion of people with mental handicap (MH) in CBR projects

Children and adults with mental handicap (intellectual impairment or learning difficulties) in developing nations in Africa and other continents, are among the least served through either Institutional-Based Rehabilitation approaches (IBR) or Community-Based Rehabilitation approaches (CBR). This booklet begins by discussing in section one some reasons for exclusion and some theoretical background for CBR. Sections two and three of the booklet offer some practical strategies for including individuals with mental handicap and their families within CBR services. This is followed by some information on evaluation in section four and finding resources in section five. The booklet builds on some of the ideas presented in several recent publications including Brian O'Toole's (1991) *Guide to Community Based Rehabilitation Services* published by UNESCO; Mike Miles' 1992 circular to MORE (Mobilising Resources) committee members entitled *Mental Handicap in CBR Projects*; Lilian Mariga's (1992) article « Community-Based Rehabilitation and Mental Handicap » and Brouillette's (1992) article « Including Individuals with Intellectual Impairments in CBR ».

Individuals with mental handicap have been largely unserved by CBR type projects in the past. This fact is apparent through reviewing reported CBR projects

in various publications. Exclusion is evidenced by reading about CBR projects described by O'Toole in the UNESCO 1991 (CBR) Guide Number 8. Of the 9 projects discussed (ten if Nepal is included), only 3 or maybe 4 (Zimbabwe, Kenya, Jamaica and Guyana) seem to include children and adults who have mental handicaps. Exclusion is also felt in reading past issues of CBR News (AHRTAG, 1988-1992). This useful publication, which is free to subscribers in developing nations (see Bibliography section), has carried more news items on mental handicap than other disability categories, few of the news items, however, relate specifically to CBR. Similarly, the Rehabilitation International and UNICEF (1990) *One in Ten* issue on CBR has no mention of mental handicap in its review of world CBR Programmes.

Instructive guides used in CBR training have provided little information about mental handicap. The excellent guide *Disabled Village Children* by Werner (1987) offers far fewer pages devoted to mental handicap than to the other disabilities, although there are relevant applications to MH throughout. The same holds true, to some extent, for the WHO Manual on CBR (Helander, et al., 1989); although this second (1989) edition offered improved coverage.

Reasons for exclusion

There are several reasons why individuals with mental handicap are quite often excluded from CBR projects and remain underserved. One reason in many developing (and developed nations) is due to the continuing misunderstanding of the differences between mental handicaps (learning difficulties) and mental illness (emotional and psychological difficulties too often associated with erratic behaviours). Miles (1992) suggests another reason may be due to inadequate CBR worker training on how to work with individuals with mental handicap. Without such information, CBR workers will lack confidence and experience to give sound advise to families. Additional reasons for exclusion include: 1) mental handicaps are less visible than physical disabilities and visual impairments; 2) the public may regard people with mental handicaps as less competent compared to other disability groups and will have low expectations for their functional potential; 3) there may be more superstitious beliefs associated with mental handicaps; 4) it may be more difficult to work with people with mental handicap especially when there are additional impairments or behaviour problems; 5) since there are no easy (medical) solutions to mental handicaps, reinforcement or rewards for instructors may be less frequent or slower in coming, especially for the untrained worker; 6) children with more severe mental handicaps may be more problematic and less desirable for integrating into community services and 7) working with individuals with mental handicaps may be thought to be more time-consuming than others who may more quickly achieve "normalized" outcome goals.

The reasons for the exclusion of individuals with mental handicaps will require more evidence from research. Miles (1992) suggests that the strategies used in CBR projects which have had a strong focus on mental handicaps have yet to be adequately studied. And, unfortunately, several general CBR projects seem destined to remain as pilot projects without ever expanding their network. There is a need for CBR projects to grow "to scale" (expanding in scope or geographic area) (RI/UNICEF, 1990). Miles (1992) suggests that CBR projects that have focused on mental handicap have survived well: (Thorburn -West Indies; Mariga - Zimbabwe; O'Toole - Guyana; Brouillettes - Nepal and Mauritius; Father Adam - Asian nations; McConkey/Lim in Malaysia; and others).

B. Definition of Community-Based Rehabilitation (CBR)

There are several ideas about what CBR is. Some professionals believe that CBR can be anything anyone wants it to be so long as it is an alternative to institutions. This "make it up as we go along" approach to CBR, while offering flexibility, does little in guiding people who want to help and empower and be democratic, systematic and effective in their efforts. There *is* a universal CBR concept and a familiar CBR approach that is fairly well defined and should be used to guide CBR development (Mendis, 1992).

Definition

One of the earliest definitions of CBR provided by the World Health Organisation (WHO) in 1981 stated:

« CBR involves measures taken (for prevention and rehabilitation) at the community level to use and build on the resources of the community including... disabled persons themselves, their families and their community as a whole. It is guided by the principles of equality, solidarity and integration. » (p. 9)

Einar Helander, a co-author of the original 1979 WHO draft CBR Manual and the revised 1989 WHO manual *Training in the community for people with disabilities* recently suggested that while CBR has typically been inspired by goodwill and dedication, it had developed in an ad hoc, unplanned manner.

Helander's (1993) more recent definition suggests:

« CBR is a strategy for improving service delivery, for providing more equitable opportunities and for promoting and protecting the human rights of disabled people". "It calls for the full and co-ordinated involvement of all levels of society: community, intermediate and national. It seeks the integration of the interventions of all relevant sectors - educational, health, legislative, social and vocational - and aims at the full representation and empowerment of disabled people. Its goal is to bring about a change; to develop a system capable of reaching all disabled people in need and to educate and involve governments and the public using in each country a level of resources that is realistic and maintainable. » (p. 3)

Comparing the two definitions may be useful in understanding some important, and perhaps unwanted CBR conceptual shifts. "Prevention" was a key component in early CBR definitions because the CBR concept grew out of the Primary Health Care (PHC) approach elaborated at the Alma Ata, USSR conference in 1978. According to the delegates at that conference: « Primary Health Care seeks to solve the main health problems in the community, providing promotive, preventive, curative and rehabilitative services... » (UN, 1979, p. 2). Notice the health context for the word "rehabilitation" that originally placed CBR within a medical model. The philosophy behind PHC is fundamental to CBR. To better understand this substitute the word "disability" for "health" in the following description of PHC: « PHC is likely to be most effective if it employs means that are understood and accepted by the community and applied by community *health* workers at a cost the community and country can afford. These community *health* workers, including traditional practitioners where applicable, will function best if they reside in the community they serve and are properly trained socially and technically to respond to its expressed *health* needs » (p. 3). The linkage between PHC and CBR for prevention is discussed later.

A second regrettable absence in the more recent CBR definition is the lack of any reference to the active participation of disabled people and their families in the CBR process. A potentially controversial third difference is the mention of the need to coordinate CBR services at the national level. CBR services are typically designed and delivered in a bottom-up fashion (community initiated and run) rather than from the top-down (outsiders determining problems and imposing solutions). There has been debate on the extent to which a project can truly belong to the community or be "bottom-up" when national, often "top-down" agents from outside the community are administratively involved. One explanation for why Primary Health Care systems have become somewhat institutionalised within many national health systems rather than operating at the grassroots level might be that some governments (or vested interest) prefer that their constituents at the community level not take medical matters into their own hands, even if they do it efficiently.

Rehabilitation

The term "Rehabilitation" (the "R" in CBR) may be alien to some parents and professionals working in services for people with mental handicaps. The term has been handed down to the present generation by post war efforts to restore mobility and other functions among injured soldiers. Since the term CBR is likely to survive for some time, it may be helpful to define rehabilitation. According to the UN (1992): « Rehabilitation is a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual psychiatric and/or social functional level of independence... It includes a wide range of measures and activities from more basic and general rehabilitation to goal orientated activities, for instance vocational rehabilitation » (p. 21). The goal of rehabilitation is the equalization of opportunities.

Throughout this booklet the term CBR is used because it is a popular term. Alternatives to the term "CBR" include Community Integrated Program or CIP (Momm and Koenig, 1989) and Neighbourhood Integrated Program (NIP). CBR can be broken into smaller units such as community-based education, community-based vocational training and employment, etc. But CBR may be considered as more than the location of where services are offered. CBR is more a sensitivity to the way in which activities are democratically planned and thoughtfully delivered. The authors of this booklet, however, have used the term "Approaches" interchangeably with Rehabilitation.

C. Normalisation, community participation and development

Community-based Rehabilitation is more of an underlying philosophy in the way in which services are developed and offered than it is a fixed method or system of services. The underpinning ideology, concept or soul of CBR is very close to the concept of **Social Advocacy (formerly Normalisation). CBR embodies the principles of normalisation. Social advocacy or the Normalising Principle was originally a Scandinavian alternative to organising services that would be more appropriate than institutions. Normalisation was first used in 1959 by Bank-Mikkelsen (1980) as « Letting the mentally retarded (individuals) obtain an existence as close to the normal as possible ». To do this would entail: « Making available to the mentally retarded (individuals) patterns and condi-**

tions of everyday life which are as close as possible to the norms and patterns of the mainstream of society » (Bengt Nirje, 1969).

David Werner (1993) in his response on reviewing the content outline of this booklet quite correctly suggested « ...much of the disabled community is very critical of the concept of being normalised (as per the above definitions) into an unjust and unfair society... » Disability groups who were the objects of rehabilitation would rather see a rehabilitation of society to make it more tolerant of diversity and to provide to all of its members greater equality and freedom. Using schools' integration as an example, while integration is seen as an ideal in social advocacy and CBR terms, segregated classrooms that focus on the acquisition of daily living skills and functional abilities for students with moderate and severe intellectual impairments may be more helpful than the ordinary or "normal" classrooms in schools that refuse to compromise a highly competitive and examination orientated curriculum and does not allow individualised instruction. Another example would be the integration of disabled people in a substandard local factory that exploits its workers.

Wolfensberger (1983) in promoting equality in societies that regard mental handicap as deviancy, devised Social Role Valorization (SRV) which emphasises « ...the creation, support and defense of valued social roles for people who are at risk of devaluation » (p. 234). According to "the conservatism corollary" one of Wolfensberger and Thomas' (1983) seven core themes that underlie SRV, a service should go somewhat overboard, if necessary and at all possible, to present the most positive images for people who are viewed in negative ways. To achieve the best images and compensate for past damage, more than "ordinary" or "normal" may be necessary. This may mean, for example, placing deinstitutionalized residents in homes in a higher income neighbourhood than would be normally expected, taken into account of course, the individual's choice of where to live and the service's budget. Wolfensberger (1991) terms the process of creating and maintaining quality participation and positive images and attitudes for devalued people in the community as *Social Advocacy.* Valued social roles defined by service users and their families should be desirable outcomes of a CBR project. Additional information on normalisation is found in The ILSMH booklet by Capie (1993) *Evaluating and Monitoring Community Services for People with Mental Handicap.*

Community development through participation

The term "Community-based" has been criticised because it is somewhat vague. "Community" has a variety of meanings across cultures. In some cultures "Community" refers to ethnic delineations. In other places the sense of community is factionated or divided by geographic or political/cultural lines. For the purpose of this booklet, community is regarded and valued as a place where people know and care for each other even in the relative absence of shared values or ideologies.

Unfortunately, the sense of community in many parts of the "modern" world is disintegrating as the nuclear and extended families break up and people begin moving away from traditional settings. A premise of this booklet is that old-fashioned intact communities are more desirable for CBR purposes than urban anonymity. It is acknowledged that a sense of community can also exist in urban "villages" or neighbourhoods.

A main element of "community" is social responsibility wherein community members are expected to pay their social dues to enjoy the rights and privileges to which they lay claim. Amitai Etzioni (1993) in his book *The Spirit of Community* suggests that social responsibility is a part of what he promotes as Communitarianism. Communitarianism calls for a move from a 'me' generation to a 'we': a reawakening to shared responsibilities that keep a community going. The 'me' generation, under the spell of modernity and 'making it' in a career or in accumulating wealth and power in the 1970s and 1980's has sacrificed the perpetuation of caring values and quality upbringing of children. CBR projects are less likely to succeed in these environments. Etzioni sees a shift to *empowerment* as a way to save the collapse of communities which in turn form the basis of a society. *Empowerment* can be defined as enabling people to participate openly and directly in making the decisions that govern their lives. Social justice is an outcome of strengthened communities. Etzioni includes the following elements for social justice for all groups:

(a) First, people have a moral responsibility to help themselves as best they can (rather than wait to be helped which risks an affront to human dignity through dependency);

(b) The second line of responsibility lies with those closest to the person in need;

(c) As a rule, every community ought to be expected to do the best it can to take care of its own;

(d) Societies (collection of communities) must help those communities whose ability to help their members is severely limited (pp. 144-146).

Holistic development

The relevance of Etzioni's principles to the concepts within CBR are striking. A deeper exploration of the nature of CBR might lead one to conclude that the task at hand is one of 'social development' more than anything else. Social development, according to Marsden and Oakley (1990), seeks to solve problems related to access to resources, the provision of basic needs, creative programming and the distribution and effective use of scarce resources. There are two ways to approach social development: the sectoral (or specialist) approach and the holistic (or integrated and generalist) approach. CBR, when correctly planned and implemented, uses the holistic approach.

Community development has evolved a system of procedures originally devised to reduce poverty and its consequences (Freire, 1972). Holistic solutions to development problems are embodied in strategies such as Community-based Integrated Rural Development or "CBIRD" developed by Save the Children (USA) to guide democratically determined improvements in a community. Cooperative planning and implementing require community consensus and participation by all factions of a village or neighbourhood. Shared ownership of the village's problems and solutions is made possible through wide participation, especially through representation by the intended recipients of the community action. CBR uses the fundamental principles of community development. CBR should be seen as an integral part of the larger process of general community development rather than something done in isolation for a specific segment of the community.

A question that might be repeatedly asked in community development work is « for whom is this development intended ? » Development is usually in direct response to assessed or expressed needs of the recipients. Development based upon the needs of other than recipients is probably neither relevant nor community based.

Participation through the local CBR management committee

A CBR local management committee is an integral component of any CBR project. The local CBR committee guides the development and implementation of CBR and usually monitors effectiveness. The CBR management committee provides an opportunity for broad community representation and participation. Details on the composition and functions of the CBR committee are found in section 3C.

D. Family participation

Parents and family members are a vital source of ideas, leadership, promotion and programme sustainability. The crucial role that family members play is well expressed throughout the League's documents. The formation of parent groups and maximising the potential of existing parent groups is a key element in CBR that includes individuals with mental handicaps. Any needs' assessment for a potential service user should include choice-making by both the parents or guardians and by the person who is to receive services (self-advocates). The combined directions given by these groups to CBR workers could reduce the risk of service users becoming "Objects of CBR".

The relationship among CBR parents and between them and CBR workers is a special one. An example of this was given at the Nairobi CBR seminar. Mrs. Sybil Tavares from Kenya provided a moving description of her own life as a mother of a daughter with mental handicap. She stressed the importance of families sharing information and providing mutual support. She, as well, addressed the need for professionals and family members to communicate frequently and to work in harmony.

The International Year of the Family (IYF) (1994) and follow-up activities offers an opportunity to promote increased family member involvement in community level activities such as 1) serving on CBR committees; 2) expanding family support and self-help groups; 3) offering training seminars, counselling services and home-based instruction to family members; and 4) stressing that the family and self-advocates are at the heart of CBR activities. The objectives for the IYF is carried in its theme, "Family: resources and responsibilities in a changing world" (UN, 1990).

There is a limit, however, to what a family can do, and asking families that have a member with a severe impairment to take on additional responsibilities can be seen as excessive. These demands can be regarded as unfair, especially to mothers, who, in many African and other developing nations already shoulder the lions share of the family's domestic and agricultural tasks. Miles (1993) and others have expressed concern over a shift in social responsibility from the government back to the community such as returning to the home recently deinstitutionalised individuals without adequate support. Families have a limited capacity to absorb what many believe should be the responsibility of the State.

CBR and mental handicap projects in Africa

Emerging trends

The self-help dynamics of families and local communities have been re-discovered and proven far more powerful and effective than was previously understood. It has been found that local people have confidence in what is to be done and are also willing and able to mobilize the necessary resources and skills required to solve their problems.

Community-based rehabilitation has demystified the rehabilitation process and given the initiative and responsibility back to the individual, the family and the community.

In spite of this, it is sad to note that most CBR approaches still are not serving the mentally handicapped community fully.

Many approaches are used by governments and non-governmental organisations to change this. The trends include:

— rehabilitation and integration by all people with disabilities, planned at central level and implemented nationally;

— small projects aiming for inclusion into national rehabilitation goals even when such goals have not been formulated yet;

— self-help activities by people with disabilities, their families, friends and neighbours;

— medical oriented approaches implemented in an outreach form, within which the team provides knowledge and skills on a regular basis to distant rural and some urban communities.

Again, in all of the above mentioned approaches, very little is done for adults and children with mental handicap. There is a lack of coordination between special education personnel and service providers. Most professionals find this segregation very difficult to deal with. Some developing countries implementing CBR have worked in close contact with special educators from planning to implementing level. Such African countries have had some good results.

It is sad to say that even the families of people with disabilities are excluding the people with mental handicaps. There are only one or two African countries with written structured programmes, and even those countries are not fully including them because of lack of understanding among leaders.

E. Service-user participation

Self-advocates' participation is an important, yet often omitted, component of CBR project planning and implementation. Service users (people with mental handicaps who use the CBR services) at the initial stages of a service development may have neither the experience nor the confidence to express their ideas about their own life goals in the community let alone CBR program direction. Self-advocates will, however, have opinions about what is correct and what is demeaning. While they might not always know precisely what to do in developing a project, they will know what not to do. Seeking advice from self-advocates might be considered time consuming and at times frustrating for those meeting deadlines, but it is also instructive, highly useful and respectful.

Most individuals with mental handicaps can best determine their own needs and often the solutions to their own problems. They have increasingly less patience in tolerating a sort of "colonisation" from professionals. Projects which involve individuals with mental handicaps are likely to be more sustainable and ecologically relevant. Consultation with service users in planning, implementation and evaluation phases encourages their affiliation and sense of ownership. It also prepares future leaders and specialists who have mental handicaps.

The creation of leisure activities for individuals with mental handicaps such as People First and Gateway Clubs will allow individuals the opportunity to exercise leadership skills and to gain confidence in their abilities. Such clubs for self-advocates could form a significant component of CBR activities.

David Werner (1992), author of *Disabled Village Children* and *Where There is No Doctor*, suggests that people with disabilities, when involved at all stages of CBR, become models of leadership, independence and general success to other individuals with disabilities. They additionally become unfailing specialists in rehabilitation services. He also notes that the major difference in general CBR and CBR designed to include people with mental handicaps is the accentuated involvement of parents and family members.

F. Disadvantages and advantages of CBR

Strengths and weaknesses are inherent in any experimental social development or rehabilitation strategy, including CBR. And when rehabilitation approaches are created for people with mental handicaps there may be additional problems and promises, and these will vary among cultures. Community perceptions about the value of individuals with mental handicaps will influence how CBR develops, the approaches taken, how service users are treated and how well the services will work (Miles, 1990). The following list of limitations and strengths of CBR are presented in the hope that those interested in initiating a CBR approach can reduce or overcome many of the associated problems.

CBR limitations

Those critical of CBR use several of the arguments presented below to justify their positions. Many of their criticisms, as well as praise, have yet to be supported by research.

a. CBR often relies too heavily on outside models and expertise in the initial stages of project development, and therefore cannot be supported or maintained without outside assistance. Dependency may develop in the process of empowering.

b. Community Rehabilitation Workers (CRW), local supervisors or any non-specialist cannot be expected to have all the skills required to effectively manage all disabilities especially the severe cases.

c. Volunteers such as parents, siblings, grandparents, scouts etc. cannot be expected to accomplish overly technical tasks, and volunteers are often unreliable and inconsistent due to their non-paid status and other commitments.

d. CBR is a concept based on inferred rather than empirical, or hard, supporting evidence (lack of research).

e. CBR services are thought of as third class because of the use of volunteer workers and the absence of the expensive equipment found in institutions.

f. CBR retains an undesirable medical bias, i.e diagnose the impairment and prescribe something to cure it.

g. CBR lacks a standardised structure and systematic approach and therefore it is difficult to evaluate how well the system is working.

h. CBR that runs as a voluntary concern denies disabled people the right to

government provided public services and lets government off their "social responsibility" hook.

Certainly CBR cannot be considered a panacea for remediating all types and degrees of disability, unfortunately no strategy can. Once CBR is more widely used and evaluated, perhaps the weaknesses outlined above will be better defined and can be overcome.

CBR strengths

a. CBR allows people with mental handicaps to participate in planning services that will directly benefit them. It therefore allows recipients to begin to take responsibility for their own lives.

b. Since CBR is Bottom-up rather than Top--down, and horizontal in design rather than vertical, CBR approaches can accurately correspond to and meet the specific needs of individuals within the community.

c. Since CBR utilises existing resources such as buildings, educational materials and local expertise, a CBR approach is often far less costly than a bureaucratically heavy institutional approach and is also more appropriate.

d. The goals of normalization or social advocacy are better met through local community integration, and neighbourhood accessibility and adaptability.

e. Since *CBR does not have to depend on outside resources* due to its grass roots nature, it is likely to continue well beyond withdrawal of any external support to the projects. CBR is also less influenced by any political changes.

f. CBR is thought to be cost-effective. It provides significant returns on the resources invested. Benefits include, in addition to extending human rights: 1) savings on later welfare payments to dependent adults; 2) productivity in terms of individual earnings and contributions to family income; and 3) taxes paid on income. The costs of CBR are thought to be less compared to those resources required for institutional approaches.

g. Traditional negative attitudes are more likely to change over a shorter amount of time within a CBR approach due to the community's increased and continual exposure to positive actions by disabled people in community settings.

h. CBR can be conducted in parallel with and actually enhance centre-based services, especially with the more severe cases of impairments (Ooi, 1992).

i. Since CBR is most effective as an integral and coordinated part of general community development, projects designed to benefit people with mental handicap will optimally benefit the entire community. Conversely, general

community development projects should directly benefit people with disabilities.

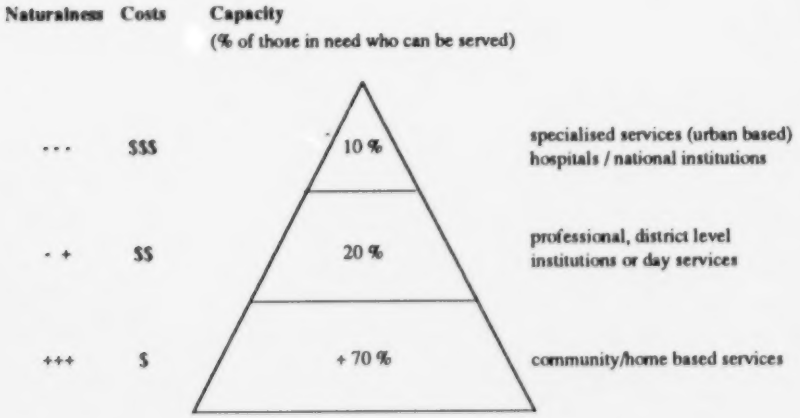
j. CBR can facilitate the work of Primary Health Care (and the reverse is also true) in health maintenance, identification of individuals in need of services and in the area of prevention.

k. CBR can serve many more individuals than can institutional approaches in the early stages of a nation's social and educational services. The CBR triangle in Figure 1 illustrates the relative naturalness (or normality), cost, and capacity to care for individuals in need of services, within three levels: Community, District and Capital City.

G. Structure of CBR

The CBR PYRAMID found in figure 1 is a concise way to illustrate the CBR approach as a way to serve a maximum number of people in need through natural and familiar environments and with mostly existing resources.

Figure 1: The CBR Pyramid



For additional information on the structural needs of CBR strategy see Miles (1990) and Momm & Koenig (1989).

H. The relationship between PHC and CBR for prevention and early intervention

There is a firm and mutually beneficial relationship between Primary Health Care (PHC) and Community-based rehabilitation. Prevention has traditionally formed an important component of CBR. Perhaps the former CBR stress on prevention has been recently de-emphasised in response to a growing ethical backlash i.e. the obsession with trying to prevent mental handicaps detracted from establishing inclusive services. Prevention is an easier response for a population that cannot accept individual differences within their community. Primary Health Care provides an infrastructure (system) through which especially newborn and very young children at risk of or having handicapping conditions can be identified, assessed and attended to. CBR links into this system in providing guidance to health personnel in diagnosing and referring children at risk. Regular pooling of information, records and resources is the major purpose of the PHC/CBR relationship. Prevention at the following three levels can be an additional part of the CBR/PHC partnership.

a. Primary: Prevention of the incidence of Impairments (the causes of mental handicaps) through public health measures (ORT, Immunizations, pre-and antenatal clinics) and public health education.

b. Secondary: Prevention of Disabilities (the difficulties created by the intellectual impairment) through intensive early interventions such as infant stimulation, adaptive aids, preschool education; and

c. Tertiary: Prevention of the Handicap (society's negative response to individual differences) through public awareness for attitude change and acceptance.

2.

How to include services to people with mental handicap in CBR projects

In an ideal world, all CBR projects would include assistance to individuals with mental handicaps. Unfortunately, for reasons discussed previously, many existing CBR services do not or will not, expand its services to include people with mental handicaps, even after all forms of persuasion. In such circumstances, an isolated CBR project exclusively for those left out may be a suitable alternative. A CBR approach for predominantly people with mental handicaps has been used in some areas of Nepal and Mauritius and elsewhere where general CBR projects did not exist, and because available project funds were for M.H. only and therefore precluded other disabilities. The following suggestions based on these and other experiences are relevant for general CBR approaches that include people with mental handicaps as well as for more isolated mentally handicapped orientated CBR projects.

A. Community integration through public acceptance

An important goal of CBR projects is the full integration of people with disabilities into their communities. Two major changes need to occur for this to

happen: 1) changes in the skills and behaviours of disabled people to more easily fit into the community and 2) changes in the members of the community to recognise, accept and accommodate individual differences. The two changes are inseparable, but changes in the community may be considered to be more important, but harder to achieve than changes in social skills.

Community level attitude changes that are more receptive to integration do not evolve on their own. Community members who become positively acquainted with a few pioneering 'model' individuals with mental handicap are more likely to advocate for the participation of greater numbers of people with mental handicaps in their midst. The community will be far more receptive to integration following sensitisation about mental handicap and through the exposure of people with mental handicap to the community. The most logical and effective place for this to happen is in the ordinary school.

Since communities will not readily accept individual differences, changing behaviours of people with mental handicap through education and social and functional skills training will help them to be more acceptable within the community. The more the community changes towards accepting individual differences, the less the individual will have to change. People will increasing have the right to be different, but integrated into the community nonetheless.

B. Developing and using individual functional curricula and methods

Successful integration into the community is often related to the relevance of special education and skill training. CBR approaches use community-based curricula that are based on a needs assessment conducted within the individual's home and other sub-environments in the community. In non-formal approaches, functional skills training based on these ecological assessments are given priority over academic skills training. Even in primary and secondary schools, it is possible to replace academic curricula with more functional, but age appropriate ones (see 2.D concerning this). In many circumstances, it is more effective for academic skills to be taught through evening classes once the adult with moderate and severe learning difficulties has mastered self-help, social and vocational or domestic living skills. Mastery of daily living skills will also enhance the mentally handicapped persons degree of community integration and quality of life. The expectations, however, of parents and teachers for an individuals' development should go far

beyond basic social and personal development. Belief in and working towards an individual's development should follow the 'active-modificational' approach rather than a passive-acceptance (accommodating) approach as described by Feuerstein (1970). The active-modificational approach will try to change the individual in significant ways by rejecting the limitations thought to be imposed by the mental handicap, and push the individual's academic and cognitive capacities to the maximum.

The methods of teaching children and adults is beyond the scope of this booklet. In brief, Community-based Workers would want to consult and work with local or district resource people specialising in the area of mental handicap. They would advise on using individualised curricula and simplified, structured teaching techniques that break learning activities into small steps and to teach each learning step until mastery. They would also advise on the use of rewards (on a quickly diminishing basis) and getting students to use new skills in practical ways to generalise learning and to sustain interest. Maintaining interest in learning is less a problem when daily living skills and other activities of interest to the child or adult are taught. Resource teachers familiar with the education of individuals with mental handicap might also be willing to provide inservice training courses to CBR workers. A good resource for CBR workers on teaching methods is C. Miles' *Teaching Mentally Handicapped Children in the Classroom.*

C. Inclusion in local preschools

The effectiveness of preschool activities such as headstart for the early stimulation and development of cognitive and social skills is well documented. One of the best places to start community-based activities is in regular preschools or nursery schools. There is typically less resistance to integration in preschools than one finds in the local primary school because preschools are administered privately or through less bureaucratic structures. Preschools also are more flexible in that they are not regulated by a national curriculum and examination systems. CBR volunteers are well utilised in integrated preschools. Places in preschools are usually scarce and a certain number should be reserved for preschool children with special needs. Bursars to assist in the fees should also be made available to support their enrolment.

Other non-formal preschool approaches include home-based teaching (such as Portage - described later), infant stimulation centres in local hospitals, clinics and

mother and infant training programmes. These are common components of comprehensive CBR systems.

D. Inclusion in neighbourhood schools

Lars Bolander from the Swedish Society for the Mentally Handicapped actively promotes integrating pupils with a range of learning difficulties into ordinary, neighbourhood schools. Bolander suggested at the Nairobi CBR seminar that Community-based Education is central to CBR and that CBR is really about education at all levels. If CBR specialists do not "mainstream" or use ordinary schools for integrated education from the beginning, ordinary schools may not accept later their community responsibility in providing « Education for All ». The range of mainstreaming approaches includes full integration into an ordinary classroom, partial integration for part of the day to self-contained classrooms. The type of integration will depend on the person's functional abilities, amount of social skills, degree of tolerance or acceptance by the non-disabled classmates and the extent to which parents and other advocates participate in the integration process (Haywood, 1992). Integrated education encourages peer support and possibilities for positive contacts that lead to acceptance and fuller societal integration. Groundwork to prepare students, staff and the community precedes successful integration. Usually if the headteacher can be convinced, others concerned will follow.

Integration approaches are typically more administratively difficult to manage than segregated special schools, but the extra work is seen to be well worth the efforts so long as the students are learning relevant and appropriate skills within the ordinary schools.

In the case of mild mental handicap or learning difficulties, it may be wiser to not identify or classify any children who are already enrolled and coping in an ordinary school. Ordinary teachers can benefit from techniques to facilitate learning through individualised and more functional learning for the children who may be slower than others. Within typical primary and secondary schools, teaching by individualised curricula is made more difficult by the presence of a national curriculum and examinations in fully integrated classrooms unless permission for exemption has been granted.

Techniques for low-cost integration where resistance to integration is high include: 1) building, on a self-help basis, a self-contained classroom cum resource room (and if funds are available, an extra regular classroom to sweeten the deal) as

a first step; 2) using specialist teacher assistants (skill-trained secondary school leavers) in ordinary classrooms; 3) developing child-to-child networks in ordinary and self-contained classrooms; 4) using itinerant specialist teachers who regularly visit from somewhere like the district resource centre; 5) developing a toy, book and equipment library from resources not available to the ordinary school and sharing these toys with the ordinary school children and teachers; 6) conducting inservice seminars for all teachers on general learning and cognition as well as on topics concerning learning difficulties. For additional information on integration see ILSMH's publication *Education for All* (1990).

E. Inclusion in local employment

Schumacher, in *Small is Beautiful* states that « Next to the family, it is work and the relationships we make there that are the true foundations of society. » Community-Based Vocational Rehabilitation offers local solutions to vocational training and employment through many of the ways described above. In a word, "networking" is the basis for identifying gaps in the local labour market and filling the needs with trained disabled workers.

Community-based approaches to employment includes domestic and subsistence forms of labour in addition to salaried positions. In agrarian economies, work for barter or in-kind payment can be more appropriate than work for pay. In places where regular integrated employment is competitive, cooperatives and revolving loan schemes are ways to establish employment alternatives. Sheltered industries and segregated employment, while less attractive in community-based, integrated terms, can be a viable alternative for training and income generation to support employees and can even subsidise CBR projects. Employees trained in sheltered environments will have a greater opportunity for assimilation into regular employment.

Where an adult with a mental handicap should live in the community would ideally be governed by local cultural practices. If it is not possible for the adult to live at home, a suitable alternative might be a small group home in the community with the minimal amount of support necessary.

3.

Specific strategies for developing CBR services

The next section provides detailed information that might be useful for implementing some of the activities common to successful CBR programmes that include individuals with mental handicaps. The details are described below under 9 major categories of activities (3.A — 3.I.).

A. General guidelines for CBR development

CBR, like most development projects, should be systematically planned and implemented. The following guidelines are offered to assist in systematic development: 1) Plan the CBR project, 2) Pilot the project on a small scale, 3) Revise/ Replicate the project as needed, 4) Expand the project as needed and 5) Evaluate the outcomes of the project (then repeat the cycle as needed). More specifically, nine steps have been identified in the process of developing a CBR project that includes mental handicaps in especially rural areas:

a. Meet with the village gate keepers (influential politicians, disabled adults, parents and existing professionals) in area to gain their ideas, acceptance and support for project. Identify and visit existing resources to gain support and

linkages.

b. Gather information (without conducting a formal survey) about known individuals with mental handicaps. Ask informed people such as parents known to have a family member with a mental handicap, educators, social workers, religious leaders and health workers. Develop a list of those who require services. Visit as many homes as possible to create interest in starting a parents' support group. Share the list with the larger CBR team and health personnel. Hold a needs assessment meeting with parents and others interested. Establish a Project Management Group that represents all social classes in the community from active parents, community leaders, volunteers and self-advocates.

c. Hold a special recreational and social event for all persons with mental handicaps. While segregated and discriminatory activities such as these are not usually a desired component of community-based approaches, they serve several purposes including: 1) an enjoyable and non-clinical method of assessing functional abilities; 2) a way for family members to meet; 3) a way to publicise the initiation of services; 4) a way to display talents and skills and 5) a way to initiate on-going recreational and social activities. Begin by establishing a skills' baseline for people who will benefit from the CBR. While this might sound overly behaviouristic, it does help in convincing related services personnel about what you are doing. There is no harm in being systematic, as long as parents and most service users can understand it.

d. Within the same week begin providing functional skill training at a community centre or a home. When you first start, be sure to include among others children and adults who are most likely to benefit and who will become quick success stories. Word of the 'magic' will spread quickly. It is just as important to dispel the myth of 'magic' and empower family members to make their own 'magic'.

e. Continue to develop Individualised community and home-based learning objectives and link into existing educational and employment resources.

f. Concurrently skill-train volunteer counterparts including family members and other volunteers as well as interested professionals in related fields.

g. Develop with the local management committee, public awareness materials based on early successes. Find business people to be on your management committee and let them sponsor much of the public information materials.

h. Continue to shift responsibility to the Local Management Committee and empower them for future project maintenance.

i. Continually review, revise and evaluate using base-line data and the feedback from family and community members as well as service users.

B. Public awareness campaigns: Using the media to create awareness, acceptance and information transfer

A major obstacle in the empowerment of individuals with mental handicap and their families at the community level is the traditional negative belief systems about the potential of people with mental handicaps. In many cultures, mental handicap remains a dark family secret, a source of shame for the father. The taboo perpetuates low expectations. These debilitating attitudes will need to be modified along with the development of services.

Public awareness about the rights, needs and abilities of persons with mental handicap is seen as a precondition for initiating a CBR project. CBR will be less successful without strong promotion of rights and full community acceptance. In the experience of the authors, the most effective means for influencing negative attitudes and stereotypes is through national and local public awareness campaigns. These need not be expensive, glossy productions, but they do need to be thoughtfully designed and sensitively delivered.

A public awareness campaign should include information on the nature and causes of mental handicap, the prevalence of mental handicap across societal classes, the types of services available and needed and the wide-ranging potential of people with mental handicap. Respected public officials and business persons who are related in some way to mental handicap should be recruited to promote acceptance. Since success breeds success, positive activities and success stories should be communicated. People with mental handicap should tell their own stories and should be depicted as active participants in their communities. The goals of a public awareness campaign are to inform about and to make popular and feasible community inclusion.

1. Some guidelines for organising a community-based public awareness campaign at the national and local levels include:

a. Involve individuals with mental handicap and parent leaders in the organisation of the campaign. Get the support of the Ministry of Information and other ministries as well as the local media;

b. Ensure only positive images of mental handicap are projected;

c. Use the success stories approach;

d. Befriend and sensitise local media people for continual media coverage;

e. Trial your materials on specialists and people with disabilities before using these materials;

f. Use the radio, posters and other popular lines of communication (barazas or town meetings);

g. Seek sponsorship for media advertisements in newspapers and radiospots from local popular businesses and civic clubs such as Lions Club and Rotary Club and obtain the assistance of popular spokespersons.

h. Consult the ILSMH booklet *Think Positive*

2. Transferring technical information

The philosophy behind CBR is based largely on transferring rehabilitation information and technology to non-professionals such as family members and volunteers in the community who can use such information on a daily basis. Miles (1990) suggests that special education and rehabilitation can be best understood in terms of information systems. Miles suggests that information-based rehabilitation is about transferring knowledge and skills from professionals to parents and volunteers who could readily use the information on the front lines of disability management. In transferring the 'magic' typically held by specialists, there is a demystification of rehabilitation and a sharing of the power of skilled assistance. The resulting larger pool of skilled helpers would lead to a significant increase in the number of people who can be assisted. The former role of professionals in delivering services has changed from being in charge of knowledge and skills to that of helping others take charge and teaching them in the process.

C. Establishment of a local CBR committee

The ownership of CBR services should belong to the community. Ownership is engendered through wide participation via the Local Management Committee (LMC). Members of the LMC typically include a balance of local leaders (elected and non-elected and from opposing political parties); family members and self-advocates; representatives from religious bodies, business and industries and from relevant sectors including social services, education, and health and general membership.

The functions of the committee include defining CBR goals and activities,

hiring personnel, networking with existing resources, fund-raising, public relations, general personnel and financial management and accounting and monitoring/ evaluation of activities including case management.

One of the greatest determinants of CBR success is leadership within the CBR Local Management Committee. The leader of the LMC must be dynamic, sincerely committed, organised and well respected. In addition, s/he should be well connected with all other services in the community.

D. Networking with local services

A successful CBR project depends on shared community resources. The leader and members of the local CBR management committee will do well to develop a close working relationship with the business community and the full range of services in the community. Achieving the desired cooperation between concerned agencies often requires marketing skills and political savvy.

E. Personnel training of local services providers

One of the most common reasons given for excluding individuals with mental handicap in CBR, as mentioned earlier, is lack of trained staff. There is an urgent need to prepare a range of helpers at all levels: people with disabilities for leadership positions, parents and siblings, pre-school and primary school teachers, Portage and other home workers, health personnel, coordinators and local supervisors and volunteers, among others.

The most convenient method for efficiently training a cadre of CBR related staff is through continual inservice training over an extended period of time. Following a three day to a week long introductory course, inservice training may continue, for example, every other Saturday or during evening sessions. Hands-on training is more useful and interesting than classroom lectures, although classroom learning is also important. See David Werner's (1982) *Helping Health Workers Learn* for more information about transferring information and non-formal educa-

tion techniques. Keep learning activities fun, interactive and short. Teach through games and group activities. Involve people with disabilities and their families as teachers. See also the League's publication by Gudalesfsky and Madduma (1992) on *Training of Persons Who Care for Persons With Mental Handicap.*

An example of a systematic CBR training programme conducted through either inservice or preservice courses (before the CBR workers begin their work) is outlined below. The information can be covered in as few as two full weeks and as long as a year depending on the entry level of participants and time available.

CBR Training Modules could include the following (around 8 - 10 hours each minimum):

a. Finding and Identifying children and adults with mental handicap in the community. Also Causes and Characteristics.

b. Assessing Functional Competencies and Learning Needs

c. Planning Individualised Programmes (IPP)

d. Management at All Levels and Record Keeping

e. Resourcing (networking) for the IPP

f. Communicating Needs (public relations) and Mobilising Community Resources (Primary Health Care, Education, Vocations, etc.)

g. Teaching Strategies, Behaviour Management and Basic Therapies

h. Public Awareness (Education) Techniques

i. Networking (involving/recruiting) With Others & Making aids

j. Skill Training (Empowering)

k. Community (culturally) specific information.

l. Techniques for monitoring and evaluating the programme.

F. Preschool/Portage Schemes

Lilian Mariga (1992) stresses the need for early intervention and for parents to become involved from the earliest identification and stimulation of the young child with mental handicap. One of the most well accepted early stimulation programmes is the Portage system of home-based intervention. Portage is increas-

ingly seen as a complementary component of CBR. The system can be used in conjunction with preschool and primary school programmes. It is flexible and easily modified (Brouillette & Brouillette, 1992).

The Portage Programme is a system of well structured learning procedures and an individualised curriculum developed to train family members in the home (and community) of a disabled child and adults (with some modifications to the Portage curriculum). Portage learning activities stimulate the acquisition of developmental milestones that will lead to greater independence and continued parental involvement. As with most popular approaches, Portage has both strengths and weaknesses. Some of these are described below.

Strengths:

a. Portage uses a highly structured yet modifiable teaching package.

b. It is highly generalisable to daily living skills because it is home and community-based.

c. It is inexpensive, available and easy to translate and adapt.

d. It is more continuous and holistic than most other segmented service approaches.

e. It helps the family to accept and bond with the child.

f. It can be used for older children with a range of impairments if the curriculum is modification.

Weaknesses:

a. Portage places an additional burden on already stretched parents, especially mothers.

b. The Portage child usually works in isolation.

c. At present, Portage is limited in its range of ages and categories of disability served.

d. Portage perhaps unfairly shifts responsibility from the community to the family.

e. There is a need for additional research evidence on the effectiveness of an expanded and modified Portage approach.

G. Recreational activities (Special Olympics)

Sporting and leisure events for individuals with mental handicaps is a normalising activity. It focuses on abilities and skills training. It can lead to integration into the typical local sports culture. It often capitalises on a strength area. Sports are a fun and socially acceptable way to bring out into the community children and adults who have been hidden away. Sporting events create opportunities for fitness training and physical therapy and without unfair competition. It also offers a way to meet others and develop a social life.

Special Olympics are sports training and competition activities designed for individuals with mental handicaps. They have been highly successful in over 60 countries and provide an opportunity for travel within ones country and for the most skilled, overseas experiences. Special Olympics has been criticised for being typically segregated and adaptive which calls attention to the athletes differences.

In spite of the criticisms, sporting events provide, in addition to the benefits listed above, an opportunity for positive media coverage and public relations. It also offers a means for volunteers to become involved in a fun activity. Very often these volunteers seek additional assignments off the playing field.

Leisure activities in many cultures include relationships with friends of both sexes. The provision of adequate information and support could foster successful relationships including marriage between individuals with mental handicap. This is seen as part of full participation in community life.

H. The development of vocations and employment

Vocational activities form a large part of CBR. Work is a normal activity for all adults. It provides an income and a social network. In some CBR projects, as much as half of all resources are directed towards vocational training and income generating opportunities.

An example of vocational development comes from Nepal's Association for the Welfare of Mentally Retarded Persons peanut butter factory. The mental handicap resource centre in the Terai, Southern Nepal, where the peanuts come from organise the shipments of peanuts to the capital Katmandu, where adults with mental handicap, in an isolated, sheltered factory produce high quality, natural peanut butter

that replaces the imported, sugar-based alternative. Some experienced workers have been integrated into open employment. Similarly, in the African nation, Mauritius, Mentally handicapped adults grow Anthurium for exportation to Europe. The skills learned at the APEIM training centre are transferred to some rural areas where the trained adults have a kitchen garden.

A resource for the development of community-based vocational development is provided by the International Labour Office (ILO) which has developed easy to use vocational training guides for employers and teachers. The ILO, African Rehabilitation Institute (ARI) and ILSMH have organized conferences on vocational rehabilitation and mental handicap for the African region. The proceedings are available from ILSMH.

I. The development of a volunteer corps

CBR depends on local resources and broad participation from community members. Building a dependable volunteer corps is essential. Even though volunteers are less reliable than paid staff, they form the basis for lasting solutions to disability services. The school leaver who volunteers with the CBR project for six months before going on to further education or work is still an asset. They do not drop-out completely. The attitudes and skills they gained during training and volunteering will last a life-time and will benefit future generations.

One of the best salary investments is in a charismatic local coordinator of volunteer services. One salary can lead to ten or more times the personnel through volunteer recruitment, training and coordination. In some CBR projects, volunteers are given a modest travel or daily allowance to off-set personal expenses.

A locally based volunteer corps can facilitate sustainability or the capacity of the CBR project to continue even without ideal factors such as a secure funding base or the presence of a dynamic CBR coordinator or committee. CBR project sustainability depends on the full participation and empowering of people with disabilities, their families and community volunteers. While the essence of a CBR project should to the extent possible come from within the community, to maintain sustainability, it is also necessary to involve government agencies. This is especially important in the education sector. Large scale integration cannot usually take place without government support. The difficulty is maintaining a balance between outside regulation and community ownership.

An African model of exemplary practice

In the multi-ethnic island nation of Mauritius, an experimental Parent Volunteer Training Program (PVTP) was established in 1982. With NFPU, Norway assistance to APEIM, the parents'association for individuals with mental handicap in Mauritius, APEIM leaders Nancy Piat and Jacqueline Laurent assisted by Jane Brouillette developed a low cost, high impact program to serve children and parents in the community.

During the initial two year period, 154 children with severe and profound mental handicaps and often additional impairments, of whom nearly half were under two years old and nearly all were under seven, were provided individualised and group therapies with at least one parent or guardian present. This support group met once a week at a local community centre or at APEIM's day centre. The families were also visited in their homes at least every other week. Adapted Portage and First Chance curricula were taught to the family members. Volunteers were recruited to assist in training family members including grandmothers and siblings. The service was free so long as a family member was present to learn therapeutic activities. Otherwise a modest fee was charged along a sliding scale.

A toy and adaptive equipment library was established. Parents rented the materials at a very modest cost in hopes to make the project as self-supporting as possible. The number of volunteers, who were provided only bus money, increased steadily. Soon, the more confident parents were further trained to be trainers as they increasingly took over the project throughout the country with APEIM assistance. By 1991, 20 nearly full-time teachers, plus parents and community volunteers were serving 424 children, nearly all under seven. There was still a waiting list of 400 children.

There was an unexpected outcome of the PVTP. Jacqueline Laurent was appointed coordinator for a large WHO supported CBR programme. She applied many of the PVTP concepts to the universal CBR for all disabilities. For a change, CBR started with people with mental handicaps and their families.

4.

Evaluating the quality of CBR services

Haunting questions about the effectiveness of CBR approaches compared to other more institutional approaches are still unanswered. The ILSMH has taken a positive first step in evaluating services in publishing a booklet by Angus Capie (1993) *Evaluating and Monitoring Community Services for People with Mental Handicap*. This booklet, available from ILSMH contains practical information to assist in monitoring and evaluation. Some additional information is provided below.

A. Why evaluate effectiveness and quality?

Many of the criticisms pointed at CBR can be responded to if we have sufficiently hard information about the value of CBR. Laura Krefting (1992) has voiced the importance for continually monitoring and evaluating CBR projects. Evaluation, if properly conducted, can answer the frequently asked questions: Is CBR cost-effective? Is it sustainable? and Does CBR really empower and enable people towards independence and integration? Confident answers to these questions could result in increased attention and support to community-based efforts.

B. How to establish a baseline

Unless specific goals and objectives of CBR are democratically developed and communicated at the beginning of a CBR project, it is difficult to determine any impact. CBR takes a long time to work even when it is correctly planned and implemented in a bottom-up manner. At the beginning of CBR activities the CBR management should ask disabled people about their quality of life and their aspirations. These statements can be supported by other data found in government offices and through interviews with local leaders. This set of information becomes the baseline or beginning profile.

C. How to determine outcome measures

In ways similar to organising the baseline information, the CBR management should set targets to accomplish. "Who will do what by when and how well?" statements form the criteria for evaluating. How often the CBR committee evaluates depends on a number of factors related to funding and the ambitiousness of the local evaluation team. Krefting (1992) has often found that uncontrollable and unintended developments from CBR such as creating enthusiasm for more general community development are a surprising outcome of CBR.

D. How to measure cost-effectiveness

The unit cost of a service is calculated by adding up all costs of the project including salaries and other costs and dividing it by the number of people who directly benefit from the project. For example if the local school costs the equivalent of $40,000 a year to run, including the depreciation to the school building, and there are 200 students in the school, the annual unit or per pupil costs is $200. If the total costs for the CBR project is $8,000 a year including in-kind donations of materials and labour (figure a volunteers salary at the local preschool teacher salary, for

example, even though you do not pay this) and 100 people directly benefit the unit cost is $80.

An important question to address is "what are the outcomes of the project". In the primary school, it is somewhat easy to measure by way of the curriculum what students should be gaining each year for the $200 cost. But what about in CBR? This is why individual programmes that contain learning objectives are important. Not only to prove cost-effectiveness but to provide encouragement to the families and disabled individuals themselves.

E. How to determine quality assurance in normalisation terms

How much better off is someone as a result of the CBR project? Has his/her quality of life changed in any observable way? Are they taking a more active part in community life? Are the services you provide in natural settings and are not harmful to the image of the person with mental handicap that you are assisting? These are examples of the types of questions we need to ask ourselves every week? (See Wolfensberger and Thomas (1983) and Capie (1993).

F. Evaluation criteria

Any evaluation of CBR projects must be culture-specific, but should address at least the following basic questions according to Krefting (1992):

a) Are people with disabilities (mental handicap) and their families involved at all levels.

b) Are the participants and service users satisfied with the services they are offered?

c) Has there been an impact?

Additional criteria that can be used as *a very rough guide to determine*

whether a project is CBR are found in appendix A.

G. Reporting success

Once you know you are doing what you set out to do, tell others the good news. Again, "Nothing breeds success quite like success." First, let your committee, service users and their families, and the volunteers know how good they are. Then tell the community, the district authorities, the national coordinating body and then the world. Use publications like *CBR News*.

5.

Resources

Very often a lack of resources are seen as a detriment to initiating CBR projects. CBR projects do not need to cost much, but will require some funding. This section is designed to assist in matching needs to resources.

A. Where to get more help and possible funding

There are several local resources for funding which can provide seed money not available elsewhere. NGOs such as civic groups may be interested to support small CBR project components. For example, the Jaycees are good at activities such as Special Olympics or funding the building of an addition to a community centre to be used as an office and library. Rotary clubs are usually good for media campaigns, etc. National religious bodies, through the local body, are good sources of small grants as well. It is far easier to find resources based on success stories and a proven track record.

When seeking funding at the international level, the stakes change. Rarely, does international assistance, whether monetary or in the form of personnel, arrive without some external culture contaminants. This might sound like an overly harsh criticism, but it is one based on reality. The additional concerns for perpetuating

dependency and potential cultural imposition though international aid assistance were expressed at an international League's MORE symposium at Vancouver in 1992. Caution and circumspection in seeking international assistance was advised by the resource group. The group also acknowledged positive aspects to international assistance such as the information that is often conveyed when aid is coupled to a foreign resource person who may also be useful in legitimising a hard to sell social development package and can shorten the project start-up time by sorting out bureaucratic entanglements. On the down-side, foreign resource people might also have conflicting approaches to development.

Among the international aid agencies that fund CBR projects are International Non-governmental organisations. A leading networking/information agency (*but not funding agency)* for CBR is AHRTAG in London. This group publishes *CBR News* which is available free to anyone living in developing nations. Their address and that of UNESCO's Co-Action Project office that receives and often supports modest requests for material assistance are found in the Bibliography section. Additional information on the roles of the U.N. agencies in disability related projects is the League's Guide *Making the Most of the United Nations* (Mittler, 1992). One of the goals devised by the League's Mobilisation of Resources (MORE) committee is to publish a detailed list of international CBR resources.

B. Writing funding proposals for CBR Projects

A helpful resource for producing funding proposals is Disabled People's International's *The Programmer's Toolkit* available from DPI (see the Bibliography section). In writing a CBR project proposal, proposers should keep in mind the guidelines that many bilateral funders use to evaluate funding applications. Some criteria used for selection that should be expressed in funding proposals are outlined below:

a. The aims of project (who really benefits) are clearly stated.

b. The project is culturally appropriate.

c. The project builds on existing institutions and structures.

d. The project uses outside experts sparingly.

e. The project uses mostly locally available and appropriate materials and personnel for sustainability.

f. The project maximises local resources: commitment, labour, materials and expertise and has letters of endorsement from contributors and authorities.

g. The project has strong community inputs which are measurable in financial terms. (The project states where local contributions will come from and how they directly relate to and include beneficiaries.

h. The project demonstrates that it is sustainable well beyond outside inputs.

i. The project phase-over (take over by the community) is calculated up front and should begin soon after the first year.

j. The project fundraising emphasis is on soft (training materials) inputs rather than hard (buildings and transportation) inputs.

k. The project budget is realistic, precise and well thought through.

6.

The need for research

The need for precise information based on hard evidence should be taken as a matter of some urgency. The momentum for CBR seems to be on the downhill slide. Much of the energy behind the grassroots movement is zapped by the confusion over what CBR is or isn't and what real effect it has on real lives in real communities. To this end, please send any available CBR information to the ILSMH MORE committee who will circulate it to those who can benefit most from it: the front-line workers of bottom-up development.

Appendix A

Is your project CBR ?

by Ron Brouillette, Ph.D.

A hopeful wave of enthusiasm is breaking down institutions for disabled individuals and replacing those institutions with new ways to help disabled people become independent and accepted in their community as well as finding community solutions to prevent impairments and disabilities.

By now we all know what Community Based Rehabilitation is. The World Health Organisation (WHO) in 1988 stated that Community Based Rehabilitation (CBR) « involves measures taken at the community level to use and build on the resources of the community including the... disabled... persons themselves, their families and their community as a whole. It is guided by the principles of equality, solidarity and integration ». But how can this definition be translated practically for those who are working with individuals with disabilities at the community level ?

Here is a checklist that you can use to see if your CBR type project fits into any of these CBR criteria. The checklist is by no means a complete list. You may want to add your own ideas/criteria to it. Put a tick next to the statements that apply to your project.

Checklist

☐ We have formed a CBR working group including disabled people, their relatives, community leaders and rehabilitation workers.

- ☐ We respect and value disabled people and believe in their capabilities.
- ☐ We listen to the needs of disabled people and plan with them.
- ☐ We work with health care workers to teach them about disabilities and how to prevent impairments.
- ☐ We work with people in the media such as radio and newspapers and with school teachers and other students to show them how they can help develo positive and accepting attitudes among community members.
- ☐ We use offices, community centres, clinics and classrooms which are already there and are open to everyone in the community.
- ☐ Our purpose is to get the helping professionals, families and community children and adults to work together with disabled children and adults to help them to help themselves.
- ☐ Local and regional leaders know and understand what we are doing.
- ☐ We use local materials in our work including making our own equipment.
- ☐ We are organised by having a plan and record keeping system for everyone we help.
- ☐ We believe that teaching the whole community about disability prevention and the rights of disabled to become included in the community and to become as independent as possible has lasting value.
- ☐ In short, the way we work is bottom-up rather than top-down.

If you have put a « yes » in at least half of these boxes, you are well on your way to having a successful CBR project.

Appendix B

Some useful addresses of resources in CBR

AHRTAG, publishers of *CBR News*

1 London Bridge Street, London WC1H 1EH, United Kingdom

CBR Unit, Institute of Child Health

University of London, 30 Guilford Street, London, United Kingdom

UNESCO Co-Action Programme

c/o ILSMH, 248 Avenue Louise, B-1050 Brussels, Belgium

c/o UNESCO, 7 Place de Fontenoy, F-75700 Paris, France

Disabled Peoples' International

101-7 Evergreen, Winnipeg, Manitoba, Canada R3L 2T

(for Programmer's Tool Kit and information on organisations of disabled people)

Bibliography

African Rehabilitation Institute (1986). "Report on the Regional Vocational and Social Rehabilitation" Workshop on Mental Retardation in Africa: November 29 - December 19, 1986, Geneva: ILO

AHRTAG (1988-1993). "CBR News". (Free to subscribers in developing nations. Write to AHRTAG, 1 London Bridge St., London, SE1 9SG England.

Baine, D. (1988). *Handicapped Children in Developing Countries*. Edmonton: University of Alberta.

Bank-Mikkelsen, N. (1980). *Denmark. in Normalisation, Social Integration and Community Services*. R.J. Flynn & K.W. Nitsch (eds.) Pro-Ed: Austin, Texas.

Brouillette, J. and Brouillette, R. (1992). The Portage System and CBR. *CBR News*, 10, 10 -11.

Brouillette, R. (1991). Developing CBR Projects: Lessons from Nepal and Mauritius. Lecture Mimeographs for CBR module. University of Manchester.

Brouillette, R. (1992) "Including Individuals with Intellectual Impairments In CBR". Background Paper for CBR & MH Seminar. Nairobi: September 11, 1992.

Capie, A. (1993). *Evaluating and Monitoring Community Services for People with Mental Handicap. A partnership Approach: the New Zealand Experience*. Brussels: ILSMH.

Disabled Peoples' International (1992). *The Programmer's Toolkit*. DPI:

(address 101-7 Evergreen, Winnipeg, Manitoba, Canada R3l 2T3).

Etzioni, Amitai (1993). *The Spirit of Community*. N.Y. Crown Publishers.

Freire P. (1972). *Pedagogy of the Oppressed*. London: Penguin.

Feuerstein, R. (1970). A dynamic approach to the causation, prevention and alleviation of retarded performance. In H. C. Haywood (Ed.) *Social-cultural aspects of mental retardation*. Baltimore: University Park Press.

Gudalesfsky, A. Madduma, C. (1992). *Training of Persons Who Care for Persons with Mental Handicap*. Brussels: ILSMH.

Haywood, C. (1992). "Reflections on Community-based Special Education". Paper presented at the International Seminar of the 20th Anniversary of the (Japan) National Institute of Special Education. Yokosuka: NISE.

Helander, E., Mendis, P., Nelson, G., & Goerdt, A. (1989). *Training in the Community for People with Disabilities*. Geneva: WHO.

Helander, E. (1993). Paper presented at "Forum on Co-ordination of Rehabilitation Programmes Funded From External Sources", Geneva. Published in CBR News No. 13 (AHRTAG, London).

Helander, E. (in press) *Prejudice and Dignity. An Introduction to CBR*. New York: UNDP.

ILSMH (1990). *Education For All*. Brussels: ILSMH.

Krefting, L. (1992). Evaluating CBR Projects. Paper presented at Kenya conference on CBR. September 3, 1992. Limuru, Kenya

Mariga, L. (1992). "Community-Based Rehabilitation and Mental Handicap" Background Paper for CBR & MH Seminar. Nairobi, Kenya September 11, 1992.

Marsden, D. and Oakley (1990). *Evaluating Social Development Projects*. Development Guidelines No. 5. London: Oxfam

Mendis, P. (1992). Community-Based Rehabilitation: Strengths and Weak-

nesses. Paper presented at Limuru, Kenya conference on CBR September 3, 1992. Sweden: ICTA, Box 510 Vallingby,.

Miles, C. (1990). *Special Education for Mentally Handicapped Pupils: A Teaching Manual.* Palo Alto: Hesperian Foundation.*

Miles, M. (1990). A Resource Centre Developing Information-Based Rehabilitation. In M. Thorburn & K. Marfo, (op. cit.)

Miles, M. (1992) "Mental Handicap in CBR Projects". Circular to ILSMH MORE Committee members, January, 1992.

Miles, M. (1993) "Comments on the (CBR Taskforce) 'list of objectives'". Circular to Victor Wahlstrom and CBR Taskforce members. Birmingham, England, 17 March 1993.

Mittler, P. (1992). *Making the Most of the United Nations.* Brussels: ILSMH.

Momm, W. & Koenig, A. (1989) Experiences and reflections on a new concept of service provision for disabled people. Geneva: ILO.

Nirje, B. (1969). The normalization principle and its human management implications. In *Changing Patterns in Residential Services for the Mentally Retarded.* R.B. Kugel and W. Wolfensberger (eds.). President's Committee on Mental Retardation: Washington, D.C.

Nerfin, Marc (1987). Neither Prince nor Merchant: Citizen. *Development Dialogue* 1, 170- 195.

Ooi, G. (1992) Centre-based Rehab and CBR - Do they Mix? *CBR News*, No. 11, May 1992.

O'Toole, B. (1987). CBR: Problems and possibilities. *European Journal of Special Needs Education*, 2, 177-190.

O'Toole, B. (1991). *Guide to Community-Based Rehabilitation Rehabilitation.* Guides for Special Education No. 8. Paris: UNESCO.

O'Toole, B. (1993). Community-Based Rehabilitation. In P. Mittler, R.

Brouillette & Harris, D (eds.) *The World Yearbook of Education,1993: Special Needs Education*. London: Kogan Page.

Rehabilitation International/UNICEF (1990). Community-Based Rehabilitation: A Ten Year Review. *One in Ten*. Vol 8 Issue 1-4 1989 and Vol, 9 Issues 1-2 1990.

Shearer, A. (1986). Building Community with people with mental handicaps, their families and friends. London: Kings Fund Publishing.

Schwartz, D. (1992). *Crossing the River: Creating a Conceptual Revolution in Community and Disability*. Boston: Brookline Books.

Thorburn, M. and Marfo, K. (1990). *Practical Approaches to Childhood Disability in Developing Countries: Insights from Experience and Research.* Jamaica: Project 3D.

United Nations (1983) *World Programme of Action Concerning Disabled Persons*. New York: UN.

United Nations Centre for Social Development and Humanitarian Affairs (1991). "The International Year of the Family: Building the Smallest Democracy at the Heart of Society". Vienna: Coordinator for IYF, UN Office at Vienna, P.O. Box 500, A-1400 Vienna, Austria.

United Nations (WHO, UNICEF and UNESCO) 1979. *Primary Health Care*. Report of the Alma Ata Conference. New York: U.N.

United Nations (1992) Ad Hoc Open Ended Working Group to Elaborate Standard Rules on the Equalization of Opportunities for Disabled Persons. 7 -10 December 1992. Vienna: Centre for Social Development and Humanitarian Affairs.

UNESCO Co-action Programme for material support to Projects. Write Tansy Bleasdale, UNESCO C0-Action Programme, 7 Place de Fontenoy, Paris 75700.

Werner, D. (1988) *Disabled Village Children*. Palo Alto: Hesperian Foundation.*

Werner, D. and Bower, B. (1982). *Helping Health Workers* Learn. Palo Alto: Hesperian Foundation.*

Werner, D. (1993). Letter to the League Concerning the CBR Task Force. March 2, 1993.

Wolfensberger, W. (1972) *Normalization*. Toronto: NIMH.

Wolfensberger, W. (1983) Social role valorization: A proposed new Term for the principle of normalization. *Mental Retardation* 21, 234-239.

Wolfensberger, W. and Thomas, S. (1983). *PASSING: Programme Analysis for Social Services Implementing Normalising Goals*. Toronto: NIMH.

Wolfensberger, W. (1991). Personal Communication. Newcastle England: Social Advocacy Workshop August 8 - 12, 1991.

WHO (1981). Disability prevention and rehabilitation. Technical Report Services No. 6b8. Geneva: World Health Organisation.

* Hesperian Foundation: P.O. Box 1692, Palo Alto, California, 94306 Fax: (415) 325-9044.

The International League of Societies for Persons with Mental Handicap (ILSMH)

Founded in 1960 by representatives of societies of parents of mentally handicapped persons, friends and professionals in the field of mental retardation, the ILSMH is devoted to defending the rights and interests of mentally handicapped persons without regard to nationality, race or religion. The League addresses problems related to mental retardation: among them are prevention, diagnosis and early treatment, education and training, economic security, social welfare and integration, guardianship, interfamilial relations, due process of law and public education.

The main objectives of the League are:

- to determine, with the help of persons with mental handicap, their families and specialists, what is required for these persons to live as close to normal lives as possible;
- to disseminate helpful information to and promote contact between member societies;
- to encourage the creation of new societies;
- to initiate and develop contacts with international organisations, governmental and non-governmental, in order to speak on behalf of member societies;
- to promulgate the basic principles set forth in the UN Declaration on the Rights of Mentally Retarded Persons.

To achieve these objectives, the League, with the help of its member societies, organizes international symposia of experts, regional conferences and world congresses. The League publishes the results of these efforts, an international newsletter translated in four languages, and various pamphlets on topics of general interest. The League has consultative status with UNESCO, UNICEF, ILO, WHO, ECOSOC and the Council of Europe, and has official relations with the European Communities and other international organizations interested in handicapped persons.

Community-based Approaches for Individuals with Mental Handicap

An African experience

© 1993 by ILSMH

International League of Societies for Persons with Mental Handicap
Ligue Internationale des Associations pour les Personnes Handicapées Mentales
Liga Internacional de Asociaciones en favor de las Personas con Deficiencia Mental
Internationale Liga von Vereinigungen für Menschen mit geistiger Behinderung

248 Avenue Louise, Box 17
B-1050 Brussels (Belgium)

Community-based Approaches for Individuals with Mental Handicap

An African Experience

ILSMH

ISBN 2-930078-01-4

56